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Estimating the cost of TB and its social impact on TB patients and their households

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Illness often poses a significant financial burden on individuals and their households, and tuberculosis (TB) is no exception. Although TB treatment is free in Nigeria, patients are likely to incur costs due to multiple visits during treatment. The purpose of this study was 1) to examine the health-seeking behaviour of TB patients and the costs borne by TB patients in Nigeria, and 2) to assess the social impact of TB disease on TB patients and their families/households. Of 260 TB patients surveyed, the majority (74.7%) were aged between 20 and 49 years. TB patients expended an average of US$52.02 (₦8323.58, at the rate of US$1 = ₦160) per person on all visits associated with diagnosis and receipt of diagnostic test results. Overall, households experienced a shortfall of about US$57.30 (₦9174.72) or 24.9% of income loss due to TB illness. Further analysis revealed that 9.7% of TB patients relied on children of school age or below to finance the costs of TB illness.

Nigeria has a high burden of tuberculosis (TB), human immunodeficiency virus (HIV) and multidrug-resistant TB (MDR-TB),[1] ranking fourth of the 22 countries with the highest global burden of TB disease.[2] Although anti-tuberculosis treatment is free in Nigeria, patients are likely to incur costs due to multiple visits during treatment. The economic costs can be an important barrier to TB patients' ability to utilise TB services and access and adhere to anti-tuberculosis treatment. Studies associated with the costs of anti-tuberculosis treatment have noted the direct costs borne by patients from fees, transport and food costs along the pathway to care.[3] In the same study, Kemp et al. found that patients spend on average about US$13, equivalent to about 18 days' wages, during treatment, and that other indirect costs such as loss of manhours at work could be greater. In another study in Nigeria by Umar et al., patients sought treatment at an average of three facilities before their diagnosis, and out-of-pocket expenditure was reported on transportation and consultation.[4] Increases in costs associated with treatment drugs as well as non-adherence were also reported.[5]

Aside from the fact that costs borne by TB patients can impact negatively on treatment outcome, many patients may continue to fall into poverty due to the high direct and indirect costs of medical treatment, and are consequently excluded from the use of health care services.[5,6] In a systematic review in China, Long et al. noted the important barrier instituted by health care providers through repeated investigations and follow-up visits.[5] Ukwaja et al. observed that many households with TB patients often fall into a 'poverty medical trap' due to the directs costs of treatment.[7] They also noted that TB patients are confronted with indirect costs such as job losses or opportunities forgone as a result of TB. This income loss was estimated at US$333.30.[7] In the study by Umar et al., the estimated time value for the hours spent seeking treatment for hospitalised and non-hospitalised patients was respectively US$517.98 and US$79.13.[4] Another study of MDR-TB patients in Ethiopia by Collins et al. found that patients frequently had to finance the costs of their health care.[8] In an attempt to cope, many patients have been known to further weaken their coping strategies by selling or leasing off their assets or resorting to borrowing, as well as the receipt of vouchers to cover certain basic costs such as food, transportation and house rental.[7–9]

While it has been established that patients accessing anti-tuberculosis treatment services bear both direct and indirect costs, the impact of these costs has yet to be sufficiently measured. This study seeks 1) to examine the direct and indirect costs borne by TB patients in Nigeria, and 2) to assess the social impact of the TB disease on TB patients and their families/households. In this study, social impact is defined as the effect of TB on patients' marital, employment and educational status as well as their sexual relationships and children's well-being.

MATERIALS AND METHODS

Nigeria is made up of 36 states and the Federal Capital Territory (FCT). The states and FCT are subdivided into six geopolitical zones, from which three geopolitical zones were drawn: the South-East, North-West and North-Central. Ebonyi, Kano and Kwara States were then randomly selected from each of the three zones. Kano State was then replaced by Kebbi State due to current security challenges in Kano state. Three local government areas (LGAs) were randomly selected from each Senatorial District in the study states. From the LGAs, two DOTS centres were purposefully selected; one with a high case load and the other with a low case load. Eligible respondents were selected from the DOTS centres for inclusion in the study. The required number of study locations and respondents per state are shown in Table 1.

Study population

The basic units of analysis in this study, TB patients, were systematically selected from the TB registers in the selected study facilities in the LGAs. The eligibility

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cost; access; tuberculosis; household; impact

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TABLE 1 Study locations and number of required respondents from each location

States	LGAs	DOTS Centres	Respondents		
			CAT1	CAT2	Total
Ebonyi	3	6	73	7	80
Kebbi	3	6	114	9	123
Kwara	3	6	57	4	61
Total	9	18	244	20	264

LGAs = local government areas; CAT = category.

criteria were Category I and II TB patients aged 15–65 years who were currently enrolled on treatment. As standard anti-tuberculosis treatment in Nigeria is given for a duration of 6 months, the respondents were sampled from TB patients enrolled on treatment between January and June 2013. The number of respondents required from each state was determined based on probability proportional to size (PPS) of the total number of TB cases in each state for January–June 2012. It was assumed that the pattern of case detection for 2012 and 2013 would be similar.

Sample size determination

Based on a total number of 2364 TB cases for quarters 1 and 2 in Ebonyi, Kebbi and Kwara States in 2012, and with a confidence interval (CI) of 6%, a sample size calculator[1] was used to estimate a sample size of 240 respondents to be included in the study. With a 10% provision for drop out or non-response, a total of 264 respondents were sampled from the three study states. This would enable a reliable statistical inference to be made at 95%CI. In all, a total of 260 TB patients took part in the survey.

Sampling units and technique

To select the required number of respondents from the sampling frames (drawn from the number of patients in the facility register) in the LGAs, the required number of respondents from each category of patients was selected using systematic random sampling (Table 1). The total number of cases in each category (*N*) was divided by the required number of respondents from each category to obtain the sampling interval (*n*) for that category. Then, beginning from a randomly chosen record/entry in the facility register, every *n*th subject was selected for inclusion in the study until the required quota for the facility was achieved.

Identification of data collectors and training

State TB Control Officers from study states assisted in the recruitment of data collectors based on the prerequisites outlined by TB CARE I. Four qualified data collectors were recruited from each study state to collect data in the state. The 12 data collectors and the three TB state coordinators were pooled and underwent a one-day training course in Abuja, run by the lead author (OO), who has experience in both quantitative and qualitative research methodologies. The training gave the data collectors and state coordinators a shared understanding of the study questionnaire and an appreciation of the objectives of the study and questionnaire administration techniques. The session for the three state TB coordinators was extended to a second day to give them further insight into the sampling plan for the study as well as the opportunity to discuss field logistics and other issues concerning the study.

Instruments and measures

Data were elicited from eligible respondents in a face-to-face interview collected at a single point in time, and responses were captured using an adapted and standardised questionnaire. Patients were interviewed in secluded corners at health facilities during their visits to the health facilities**.** The Tool to Estimate Patients' Costs, developed by the KNCV Tuberculosis Foundation (KNCV), the World Health Organization (WHO) and the Japan Anti-Tuberculosis Association (JATA), was adapted for the study. The indicators measured are direct costs to patients before and during diagnosis, patient and health system delays, indirect costs before and during diagnosis, direct patient costs during treatment, indirect costs during treatment, total costs of TB to patients, productivity, coping costs, guardian costs, additional health costs (including HIV), willingness and ability to pay, income and affordability of TB and health care, health insurance, gender/social costs of TB and socio-economic variables.

Data analysis

Data were entered using the Statistical Package for Social Sciences v. 20.0 (SPSS, IBM Corp., NY, USA) to describe relevant variables and indicators. Descriptive statistics are provided for all variables, including frequencies, percentages for categorical variables and mean and standard deviation for continuous variables. Comparisons between the states were performed using the χ^2 test. Cross tabulations between independent and dependent variables were conducted where deemed necessary. All financial calculations are presented at an exchange rate of US$1 = ₦160 for the year 2013.

Ethical considerations

The National Tuberculosis and Leprosy Control Programme (NTBLCP) secured ethical clearance from the National Health Research Ethics Committee (NHREC) for the survey. Informed consent was obtained by handwritten or thumb print signature from participating patients. Participants' names were not required and were not recorded. Interviewers ensured confidentiality of data by conducting interviews in private settings with minimal distractions from staff and other patients.

RESULTS

Of 260 TB patients included in the study, 225 (87.6%) were Category I patients, 30 (11.7%) were Category II patients (retreatment cases) and 2 (1.2%) were smear-negative or extra-pulmonary TB (EPTB) patients. Table 2 presents the sociodemographic profiles of respondents in the study. The majority of the patients were aged between 20 and 49 years (74.7%), with a mean age of 37.7 ± 12.9 years (40.1 ± 12.6 years among men and 34.6 ± 12.7 years among women). More than half of the respondents were male (57.8%), more people lived in rural (43.3%) than urban areas (31.8%), and 24.9% resided in urban slums. A little over a quarter of the patients had no formal education (29.5%); the majority had secondary education (39%), and only 16.1% were graduates. The majority of the patients (69.8%) were engaged in informal employment; only 15% had formal employment, 5% were involved in housework and 2.7% were students. The study participants' income level per month indicated that a little less than half (48.4%) were not earning income, 17.3% had earnings of <$93.75 (₦15 000) per month, while the rest (34.4%) earned more than $93.75 (₦15 000) per month. The mean number of individuals living in a household with a TB patient from the survey was 5.9. The mean average household size of TB patients was 6.08 in rural areas, 5.8 in urban areas and 5.74 in urban slums.

Health-seeking behaviour of tuberculosis patients

A major area of concern in the management of TB is delay in seeking and obtaining treatment after onset of symptoms, as this

TABLE 2 Respondents' demographic profile

Background characteristics	Respondents *n* (%)
Sex	
Male	144 (57.8)
Female	105 (42.2)
Age, years	
15–19	8 (3.2)
20–29	63 (25.3)
30–39	69 (27.7)
40–49	54 (21.7)
50–59	27 (10.8)
60–70	28 (11.2)
Residence	
Urban	78 (31.8)
Urban slum	61 (24.9)
Rural	106 (43.3)
Other	2 (0.8)
Education	
Illiterate/no schooling	75 (29.5)
Primary	39 (15.4)
Secondary	99 (39.0)
Graduate	41 (16.1)
Employment status	
Formal work	38 (15.0)
Informal work	176 (69.8)
Housework	12 (4.7)
Students	7 (2.7)
Others	19 (7.8)
Monthly income, NGN	
<₦5 000	5 (5.4)
₦6–10 000	5 (5.4)
₦11–15 000	6 (6.5)
> ₦15 000	32 (34.4)
No income	45 (48.4)
Ethnic group	
Hausa/Fulani	97 (38.6)
Igbo	79 (31.5)
Yoruba	51 (20.3)
Other	24 (9.6)
Individuals in TB household, *n* (mean)	
Urban	78 (5.84)
Urban slum	60 (5.75)
Rural	102 (6.08)

NGN = Nigerian naira; TB = tuberculosis.

can increase the infectivity of the patient and lead to more serious illness and additional costs. There were delays reported among TB patients in seeking treatment. The average time before patients sought treatment ranged from 2.6 weeks for cough with blood to 5.3 weeks for cough without blood. A total average delay of up to 4.3 weeks was observed among TB patients in the study before commencement of treatment.

Patients were most likely to seek treatment and advice from secondary health facilities (46.2%), followed by primary health care (17%) and private hospitals or clinics (14.5%). About 10.3% of respondents also sought treatment and advice from pharmacy/patent medicine vendors (PMVs) or herbalists (9.5%). The majority of patients (50%) sought treatment first at the out-patient services, while 12.9% first visited private hospitals and 10.7% first visited a pharmacy/PMV. Those who mentioned visiting non-government-owned facilities were asked to give reasons for their decision. Two prominent reasons given were distance to health facilities and belief system, mentioned by 26% of the respondents. Other reasons cited by 12% of the patients were waiting time, while 8% mentioned that the services were too expensive and mistrust of government health services.

The economic cost of accessing tuberculosis services in health facilities

TB patients expended an average of US$52.02 (₦8323.58) each on all visits associated with diagnosis and receipt of diagnostic test results. Travel costs, food and accommodation accounted for about 68.1% of the total costs incurred (Table 3). Other direct costs of anti-tuberculosis treatment included charges for administration (12.8%), tests (5.3%), X-rays (6.2%) and drugs (7.4%). The estimated average income per month for all persons in the house, including patients' income, welfare payments, government assistance and other social support before TB illness, was US$230.34 (₦36 853.64), while the average income per household after the illness was estimated at $173.00 (₦27 678.92), resulting in a shortfall of about $57.30 (₦9174.72), or 24.9% of income lost to the household in the study. This was calculated based on the respondents' estimate of household income before and after TB illness.

Social impact of illness on tuberculosis patients

Table 4 shows the effects of TB illness on the social or private lives of TB patients according to patient characteristics. Over 66% of all respondents experienced no negative social effects from TB illness. However, 11.7% experienced loss of work, 4.4% divorced or separated from their spouses or partners, while 4.3% experienced disruption of their sexual life. Another 2.6% of respondents dropped out of school or had a sick child as a result of TB. More men (2.6%) than women (1.8%) experienced divorce or separation from their spouse or partner. Similarly, more men (7.4%) than women (4.3%) reported loss of work. However, more women (6.1%) than men (4.8%) in the study indicated disruption of day-to-day activities, separation from friends and reduced attendance of social/family gatherings as a result of TB illness. Pulmonary smear-positive TB patients (11.4%) were more likely to report job losses and disruption of their sexual life (3.9%) than pulmonary smear-negative and EPTB patients.

To understand how TB patients coped with the loss of income and the social impact of TB illness on TB households, the respondents' coping strategies were assessed. No TB patients in the study had private or government medical insurance. Possible coping strategies devised by patients to survive during their illness included borrowing money to cover the costs (26.3%). Of the 65 respondents who borrowed money, an average of US $206.98 (₦33 117.74) was borrowed per person, and most funds were borrowed from neighbours/friends (54.0%), family (24.6%) and co-operatives (20.0%). A third (19 respondents) of those who borrowed money paid interest rates ranging from 6% to more than 10% on the loan. More males (16.6%) than females (9.7%) borrowed money to cover the costs of TB; those with no work or those engaged in informal work were more likely to borrow (19.4%), compared with those doing housework (1.6%), formal work (1.2%) and students (0.8%). A total of 58 (22.8%) respondents indicated selling property to finance the cost of their TB. Of those who sold property, the majority sold livestock (48%), followed by household items (33%), farm produce (25%) and transport/vehicles (10.4%). The total funds generated by study participants from the sale of property to finance TB were estimated at

TABLE 3 Amount spent per patient for all visits to health facility to access pre-diagnostic and diagnostic services

Visits	Administrative costs (consultative registration) NGN	Test costs (for sputum or others except X-ray) NGN	X-ray costs (includes sending X-rays to radiologist) NGN	Drug costs (all kinds, total) NGN	Travel costs (total) NGN	Food costs (total) NGN	Accommodation costs (total) NGN	Sub-total costs NGN	Insurance reimburse-ment*
1	592.92	282.77	417.96	446	813.15	1001.19	1041.35	4595.35	NA
2	155.96	75.00	87.12	79.46	453.81	542.31	670.19	2063.85	NA
3	321.73	46.19	13.2	93.27	259.23	87.73	365.38	1186.81	NA
4	5	22.31	0.19	0	114.08	58.88	85.19	285.65	NA
5	1.15	8.27	0.19	0	53.31	14.23	0	77.15	NA
6	0.38	3.46	0	0	28.27	6.27	60.38	98.77	NA
7	0	0.38	0	0	11.77	1.04	0	13.19	NA
8	0	0.77	0	0	0.38	0.23	0	1.38	NA
9	0	0.77	0	0	0.38	0.27	0	1.42	NA
Total	1077.15	439.92	518.73	618.73	1734.39	1712.15	2222.5	8323.59	NA
% of total (n = 8323.57)	12.79	5.29	6.23	7.43	20.84	20.57	26.70		

*If yes, amount, if no, NA.
NGN = Nigerian naira.

TABLE 4 Distribution of the effects of TB illness on the social or private lives of TB patients by patient characteristics

Patient characteristics	No effect (n = 157) %	Divorce/separated from spouse or partner (n = 8) %	Loss of job (n = 27) %	Dropped out of school (n = 5) %	Disruption of sexual life (n = 10) %	Sick child (n = 3) %	Other effects (n = 27) %	Total n
Sex								
Male	38.7	2.6	7.4	0.4	2.6	0.9	4.8	132
Female	27.4	1.8	4.3	0.9	1.7	0.4	6.1	92
Level of education								
No school	24.2	1.3	0.8	0	0	0	2.1	67
Primary	7.6	1.2	3.4	0	1.7	0	1.3	36
Secondary	23.7	0.8	5.9	1.3	2.1	1.3	5.1	95
Graduate	11.4	0.4	1.3	0	0	0	2.5	37
Type of TB								
Pulmonary smear-positive	48.2	2.1	11.4	1.3	3.9	0	7.9	173
Pulmonary smear-negative	16.7	1.3	0	0	0.4	1.3	3.1	52
Extra-pulmonary	1.3	0	0	0	0	0	0	3
Treatment phase								
Intensive	30.4	2.5	6.8	1.3	3.4	0.8	3.8	116
Continuation	35.9	1.7	4.8	0	0.8	0.4	7.6	121
Total	66.2	3.4	11.4	2.1	4.2	1.3	11.4	237

TB = tuberculosis.

$289.08 (₦46 252.83). However, the estimated total market value of the various items sold by study participants after TB illness was $540.72 (₦86 515.79) as mentioned by participants, resulting in a total loss of $251.64 (₦40 262), almost half (47%) of expected revenue. When TB patients were asked if any of their children of school age or below worked to finance the costs of TB, only 12 respondents (9.7%) replied that they relied on children of school age or below to finance the costs of TB illness.

DISCUSSION

The study findings show that TB patients experienced social impact of their TB illness such as the loss of jobs, divorce/separation or dropout from school. However, more males than females experienced loss of jobs. Pulmonary smear-positive TB patients were more likely to lose their jobs than other categories of TB patients, which may be suggestive of stigma. None of the patients in the study had medical insurance. This was also observed in the study by Collins et al. in Ethiopia, where only one MDR-TB patient reported having medical insurance.[8] Given the lack of medical insurance for most patients in the study, there is a need for governments to ensure health coverage for patients to prevent exclusion from treatment.

TB patients experienced delays of up to 4.3 weeks before seeking treatment, although the delays were shorter than reported by Odusanya and Babafemi, who reported a median delay of 8 weeks in their study.[10] Ukwaja et al. observed similar findings in their study, where about two thirds of patients sampled did not seek treatment until about 4 weeks after the onset of symptoms.[7] TB patients bear other costs associated with anti-tuberculosis treatment and diagnosis despite the fact that anti-tuberculosis treatment is provided free in Nigeria.[4,9,11] Patients bore an average of

US$52.02 (₦8323.58) per person on all visits related to diagnosis and receipt of test results, an amount comparable to the loss to TB patients' households (US$57.30 [₦9174.72]) as a result of TB illness. Travel costs were the dominant cost borne by patients, an indication that TB services are not within easy reach of those who need them. As TB is associated with poverty, these extra costs pose significant barriers to patients' ability to access TB services. The decision by patients to access other care services may be connected to distance from the health care facilities or reduced household income.[5,12]

TB patients also had to sell property such as livestock, farm produce or household items, similar to findings by Ukwaja et al.,[7] and/or borrow money to finance the cost of their treatment, a situation that further impoverishes the patients and erodes their social security and means of livelihood.

The effect of the costs of treatment on the impact of TB illness could be further explored in another study. The study may have been limited by recall bias in the estimation of the costs associated with diagnosis and treatment, and, despite the fact that data collectors were provided with training prior to field work, it was observed that some vital responses from respondents were missing. For example, only 249 of the 260 respondents gave their sex and age. However, as the minimum sample size required for the study was 240 respondents, the study had sufficient power to support the inferences drawn.

CONCLUSION

This study establishes and quantifies the extra costs borne by TB patients in accessing TB diagnosis and treatment in Nigeria. Costs borne by patients are due to travel, accommodation and food costs, which has an impact on household income. TB diagnostic and treatment services need to be further decentralised and made available within the reach of patients. The social impact of TB disease on patients and their households was also established in the study. The loss of work by more smear-positive TB patients is of concern, and should be addressed through workplace policies.

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La maladie constitue souvent un lourd fardeau financier pour les patients et leurs familles et il en va de même pour la tuberculose (TB). Même si le traitement de la TB est gratuit au Nigéria, les patients doivent supporter les coûts liés aux nombreuses consultations pendant le traitement. Le but de cette étude a été 1) d'examiner le comportement des patients TB en matière de recherche de soins et les coûts supportés par ces patients au Nigéria, et 2) d'évaluer l'impact social de la TB maladie sur les patients et leurs familles/foyers. Sur 260 patients TB de l'enquête, la majorité (74,7%) étaient âgés de 20 à 49 ans. Ils ont dépensé en moyenne US$52,02 (8323,58 nairas nigériens, au taux de change de $1 = ₦160) par personne pour les consultations liées au diagnostic et la réception des résultats de leurs examens. Au total, les foyers ont eu un déficit d'environ US$57,30 (₦9174,72) ou 24,9% de perte de revenus due à la maladie. Une analyse plus approfondie a révélé que 9,7% des patients TB comptaient sur les enfants d'âge scolaire ou préscolaire pour financer les coûts de la TB.

Las enfermedades suelen imponer una considerable carga económica a los pacientes y sus hogares y la tuberculosis (TB) no constituye una excepción. Aunque el tratamiento antituberculoso sea gratuito en Nigeria, con frecuencia los pacientes deben asumir los gastos que generan las múltiples consultas durante el tratamiento. El presente estudio tuvo los siguientes objetivos: 1) examinar el comportamiento de búsqueda de atención sanitaria de los pacientes aquejados de TB y los costos que sufragan estos pacientes en Nigeria; y 2) evaluar la repercusión social de la enfermedad tuberculosa sobre los pacientes, sus familias y sus hogares. De los 260 pacientes con TB que participaron en el estudio, la mayoría tenía entre 20 y 49 años de edad (74,7%). En promedio, los gastos de cada paciente por todas las consultas asociadas con el diagnóstico y la recepción de los resultados de las pruebas fue 52,02 USD (u 8323,58 nairas; 1 USD = 160 NGD). En general, debido a la enfermedad tuberculosa el ingreso de los hogares sufrió una pérdida cercana a 57,30 USD (o 9174,72 NGD) o de una disminución del 24,9%. Un análisis más detallado reveló que un 9,7% de los pacientes con TB dependía de los hijos en edad escolar o menores para financiar los costos de la enfermedad.

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